May 13, 2015

Michigan Achieving a Better Life Experience (ABLE) Act (HB 4541, 4542, 4543, 4544)

Michigan House Committee on Financial Services

Chair: Representative Anthony Forlini

Majority Vice-Chair: Representative Peter Pettalia Minority Vice-Chair: Representative Henry Yanez

Room 326 Anderson House Office Building 124 North Capital Avenue Lansing, Michigan

Good Morning,

Chairman Forlini, Representative Pettalia, Representative Yanez and to all the members of the committee, thank you for the opportunity to speak to you today.

First, I would like to share a little about my daughter Katie. She is 9 years old and in the third grade. She goes to dance class, likes to play baseball and basketball, loves to ride her bike and run really fast. She likes pizza, hotdogs, popcorn and ice-cream. She hates going to bed early, cleaning her room and commercials. Katie wants to learn how to drive a car, graduate from high school and go to college. Then, she hopes to be prepared to get a job, buy a house and save for her future. She is just like many of you! It just so happens, Katie was born with Down syndrome and she wants to Achieve a Better Life Experience.

My name is Traci Lambert and I am speaking here today as a Michigan Ambassador for the National Down Syndrome Association (NDSS) and as a representative of the Down Syndrome Association of North West Michigan. But more importantly, I am here today as a mom to advocate for passage of the Michigan ABLE Act for my daughter Katle and many other individuals with Down syndrome living in the great state of Michigan.

NDSS is the leading national advocacy organization for the value, acceptance and inclusion of people with Down syndrome. NDSS was one of the lead organizations in creating and passing the Stephen E. Beck Achieving a Better Life Experience Act, better known as the ABLE Act of 2014. This bill was 8 years in the making and I have been fortunate to travel to Washington during the last two years and advocate to our US Senators and Representatives to pass the ABLE Act. On December 19, 2014, President Obama signed the bill into law. Disability advocacy groups around the country celebrated the overwhelming bipartisan support of the ABLE Act and consider it one of the most significant pieces of legislation for individuals with disabilities since the American Disabilities Act.

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Ten years ago in July, I held my daughter Katie for the very first time. Then, just 24 hours into her short, beautiful life, our doctor informed us he would like to test her for Down syndrome. Suddenly, the next 20-30 years of her life flashed before my eyes. Would she be healthy. Would she be teased or would she be loved and respected. Would she get a quality education, where would she go to college. What kind of job would she get, would she be treated fairly and as an equal. Where would she live, would she need help. And then, just as quickly, I thought why would she not have all the same opportunities as any other child. These were the exact same questions and concerns we had with Katie's sister. I knew I certainly wouldn't treat her any differently or have less expectations.

Although Katle was born with a congenital heart defect, she did not require surgery and her heart healed on its own. Katle was later diagnosed with an instability in the upper vertebrae of her neck, but again the prognosis was encouraging. We are very fortunate that Katle is in good health and no longer required regular appointments with the pediatric specialists for either of these conditions. She continues to see an ENT, ophthalmologist and dentist on a regular basis. In addition to Katle's health needs, we began early interventions to support Katle's speech, fine and gross motor skills along and development. Soon we were discussing preschools and kindergarten. It was through these experiences, that I realized I had a more important job to do and went from working full time to barely part time. Due to our family's reduced income and because of Katle's disability, it was suggested we may qualify for Supplemental Security Income.

So, we inquired about the SSI program and were very surprised on what we learned about income and resource limits. But more importantly was what we learned about how Katie would or wouldn't be able to save and plan for her future. Along with a savings account, we had already started a college savings plan for her sister Claire. We wondered if we should do the same for Katie. I have had people ask me, "will Katie always live with you?" How do you answer that? As a parent, you always want to protect your children, so silently in my heart I answered yes. But truthfully, I would tell people, I hope not. I want both my children to be happy. I hope we are helping them build a solid foundation through our family values and beliefs, their education, the friends they choose and decisions they make, to be independent and work hard and always try first. But also know, if they need help or support it is there. And more importantly, to understand that help or support from a friend or family member, or even from a state or federal program, should only be considered temporary and to not become dependent on supports and services. These are the expectations for both my children, one with Down syndrome and one without.

And so I came to understand that there was the potential in Katie's future to not be treated equally or fairly, when it came to saving for college, to live independently or even save money for emergencies. To maintain eligibility for SSI in Michigan, a single person is limited to \$2000 in resources, such as checking and saving accounts, savings bonds, and certain personal property. There are also limits on monthly income and individual can earn. How does a person with a disability, who may have higher than average medical expenses, additional educational or job training expenses or even challenges with securing meaningful employment live independently or save money on such a limited income?

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ABLE accounts will allow individuals with disabilities and their families to contribute to a tax-exempt savings account that can be used for disability related expenses such as housing and transportation, medical and dental, education and job training. All the things we began saving for with our first jobs. An ABLE account will allow Katie and others with Down syndrome the same type of flexible savings tools that their non-disabled peers have through college savings accounts, health savings accounts or individual retirement accounts.

Our leaders in Washington, over 85% of Congress, came to together and agreed that the ABLE Act was an equal and fair solution. So today, I urge you, our leaders in Michigan to do the same and pass the Michigan Able Act, so my daughter Katie can take the \$1,987.65 in her 529 plan and turn it into a 529 ABLE Account.

Thank you Chairman Forlini, for your leadership and sponsorship and also to Representative Lucido for sponsoring the ABLE bills in Michigan.

Respectfully submitted,

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